Family Caregiving as a Grantmaking Area: Current Focus and Future Trends

July 2002

By

FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

For

The U.S. Administration on Aging
About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.
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Executive Summary

Caregiving is a public health issue that will preoccupy American families well into the 21st century, as the baby boomers join the ranks of Older Americans. Family members and friends are the backbone of our long-term care system, providing largely unpaid assistance to loved ones with chronic illnesses or disabilities. A substantial body of research has shown that prolonged caregiving has negative effects on the emotional and physical health of caregivers, even though it is willingly undertaken and often a great source of personal satisfaction.

As the magnitude of family caregiving grows, American society is struggling to find ways to support families. Recent federal law – the National Family Support Program (NFCSP), enacted under the Older Americans Act Amendments of 2000 – supports the strengthening of family and informal caregivers of older persons. The passage of the NFCSP was the first federal legislation that specifically recognized the needs of family caregivers and provided support services to sustain family and friends in their caregiving role.

While the federal government is playing an increasingly important role in helping to finance caregiver support services to older persons – as evidenced by the passage of the NFCSP -- states and local governments, as well as the private sector and philanthropic community, have also taken steps in recent years to develop policies and programs that support and sustain family and informal caregiving. To meet the growing needs of caregiving families and leverage support for caregiver initiatives, partnerships and collaborations between the public and private sectors are likely to increase. Decision makers in public policy and private philanthropy are increasingly recognizing that families need an array of supports if they are to maintain their critical role in the provision of long-term care.

Purpose of Study:
The purpose of this study is to increase understanding about foundation activity, interest and philanthropic trends in the area of family caregiving. This report presents results of a 2002 grantmaker survey and interviews with selected foundation leaders that highlight:

Access to and use of information on family caregiving
◆ Awareness of the NFCSP
◆ Current grantmaking focus on caregiving
◆ Future interest in funding caregiving initiatives

Methods:
This study builds on the 1999 Grotta Foundation survey to examine grantmaking support for family elder caregiving. The survey instrument used in this study was adapted from the 1999 Grotta survey in consultation with staff from Grantmakers in Aging, Grantmakers In Health, and a few selected foundation leaders. The semi-structured survey instrument consisted of 10 questions, which was designed to be completed in ten to fifteen minutes.

To complement the written survey, brief telephone interviews were conducted with five foundation leaders active in the aging and family caregiving arena at the local, regional, and national levels. The interviews served to provide more in-depth information about current and future foundation interest and trends in family caregiving.
Of the 243 foundations (unduplicated) that received the survey, 117 foundations responded, resulting in a 48% response rate. Responding foundations were located in 30 states and the District of Columbia. Ninety-eight of the 117 (84%) responding foundations identified themselves as grantmakers with a current or potential interest in funding family caregiver initiatives, and form the basis of the analyses in this report.

**Key Findings and Conclusions:**

- Family caregiving is on the funding agenda for the great majority of grantmakers who responded to this survey.
- Grantmakers are most likely to fund family caregiving, now and in the future, within the broader context of home and community-based long-term care for older persons and their families.
- While most of the foundations in this study reported interest in caregiving, a sizeable proportion had no current grantmaking focus on family caregiving for older persons.
- Most grantmakers with a current focus or potential interest in caregiving have some access to information on this population.
- Fact sheets, websites and white papers/articles topped the list of most useful modes of information delivery on family caregiving issues.
- Local and regional foundations showed a high level of interest in family caregiving overall.
- Foundations are likely to fund family caregiving initiatives in the future if the community need for family caregiver support is seen as high and if family caregiving is more widely recognized as a pressing social concern.
- Foundations expressed a high interest in replicating existing, effective model programs or promoting new model programs to sustain families in their caregiving role.
- While foundations had a substantial interest in family caregiving, they were not well informed about the National Family Caregiver Support Program (NFCSP).
- Partnerships – among funders and between the public and private sectors – are important factors in determining future foundation support in caregiving.

**Most foundations in this survey expressed interest in meeting with government entities and other grantmakers to explore the synergy of the public and independent sectors in supporting family caregiving.**
Introduction

Caregiving will preoccupy American families well into the 21st century, as the baby boomers join the ranks of older Americans. The future looks very unlike the past. A number of societal dynamics – demography, healthcare financing, family structure, and medical advances – have pushed caregiving and long-term care to center stage at the national, state and local levels (Binstock, Cluff & Von Mering, 1996).

Family members and other informal caregivers are the backbone of our long-term care system, providing largely unpaid assistance to loved ones with chronic illnesses or disabilities. The economic value of care provided by families is staggering. At an estimated value of $196 billion nationally (in 1997 dollars), informal caregiving eclipses home health care ($32 billion) and nursing home care ($83 billion) (Arno, Levine & Memmott, 1999).

More and more Americans find themselves providing care to loved ones with a chronic illness or disability. Virtually all older persons (about 95%) living in non-institutionalized settings receive at least some assistance from relatives and friends. About two out of three (67%) older persons living in the community rely solely on informal help, mainly from wives and adult daughters (Stone, 2000).

Caregiving, one of the most personal family issues, is now a growing public health concern. A body of research has shown that providing care to older people often exacts a heavy emotional, physical, and financial toll on the caregiver. Prolonged caregiving has negative effects on the emotional and physical health of caregivers, even though it is willingly undertaken and often a source of great personal satisfaction. The emotional and physical strain of caring for an older relative is often exacerbated by worries over paying for care. The financial impact of caregiving is most apparent for family caregivers when it affects their ability to work. Research has shown that working caregivers suffer significant losses in career development, salary and retirement income, and substantial out-of-pocket expenses as a result of their caregiving obligations (Mature Market Institute, 1999).

Recent federal law – the National Family Caregiver Support Program (NFCSP), enacted under the Older Americans Act Amendments of 2000 – supports the strengthening of family and informal caregivers of older persons. The passage of the NFCSP was the first federal legislation that specifically recognized the needs of family caregivers and provided support services to sustain family and friends in their caregiving roles.

While the federal government is playing an increasingly important role in helping to finance caregiver support services to older persons – as evidenced by the passage of the NFCSP -- states and local governments, as well as the private sector, have also taken steps in recent years to develop policies and programs that support and sustain family and informal caregiving. Private foundations interested in aging and health care have developed strategies and initiatives to identify and support a range of programs and services designed to help family caregivers (Gutheil & Chernesky, 2001).
To meet the growing needs of caregiving families and leverage support for caregiver initiatives, partnerships and collaborations between the public and private sectors are likely to increase. Decision makers in public policy and private philanthropy are increasingly recognizing that families need an array of supports if they are to maintain their critical role in the provision of long-term care.

**Purpose of Study:**

The purpose of this study is to increase understanding about foundation activity, interest and philanthropic trends in the area of family caregiving. The study builds on the 1999 survey undertaken by the Grotta Foundation to examine grantmaking support for family elder caregiving (Gutheil & Chernesky, 1999). This current report presents results of a 2002 grantmaker survey and interviews with selected foundation leaders that highlight:

- Access to and use of information on family caregiving
- Awareness of the NFCSP
- Current grantmaking focus on caregiving
- Future interest in funding caregiving initiatives

It is the authors’ hope that this report will be helpful to a number of audiences who are interested in sustaining family caregivers: grantmakers, public policymakers, service providers, researchers, and families themselves. Caregiving will remain an intrinsic part of the experience of American families well into the future. We can no longer afford not to act – our own future and that of our parents, grandparents and children depend on it.
Methodology

Written Surveys:

A survey instrument was adapted from the 1999 Grotta survey in consultation with staff from Grantmakers in Aging, Grantmakers In Health, and a few selected foundation leaders. Grantmakers in Aging (GIA) is an educational membership organization of grantmakers active in the field of aging. Similarly, Grantmakers In Health (GIH) is an educational membership organization dedicated to helping foundations and corporate giving programs improve the nation’s health.

For the present study, the term “family caregiver” was defined as “family, friends, or neighbors who provide care to older persons (aged 60+) who need help with tasks of daily living. The caregiver can be of any age.” The semi-structured survey instrument\(^1\) consisted of 10 questions that addressed:

- Background characteristics of the foundation (e.g., size of grant program)
- Access to and use of information on family caregiving
- Awareness of the NFCSP
- Current focus and activity on family caregiving
- Future interest in and focus on family caregiving (i.e., next three to five years).

The survey instrument primarily consisted of multiple-choice questions and short write-in responses. Space was also provided for comments. On average, the survey was estimated to take ten to fifteen minutes to complete. Foundations were encouraged, in a cover letter, to respond even if they did not currently fund caregiving projects.

A total of 372 written surveys were sent on March 1, 2002 (first mailing) to the mailing lists provided by GIA (n = 173) and GIH (n =199). Of the 372 surveys sent out, 129 were deemed duplicative as they were sent to multiple staff within the same foundation. For the subsequent two follow-up mailings, only one foundation executive was sent the survey, for an unduplicated count of 243 foundations. A second follow-up mailing to the foundations was sent out on March 18, 2002. The third and final mailing was sent out on April 3, 2002. A total of six foundations returned multiple surveys as a result of the first mailing, which included, in some instances, more than one staff person in a foundation. For purposes of analysis, we used only one response per foundation, from the most senior foundation executive.

Telephone Interviews:

To complement the written survey, telephone interviews were conducted with five grantmakers, representing individuals and foundations known to be leaders in aging or health philanthropy at the national, state, or local levels. On average, the telephone interviews took fifteen minutes to

\(^1\) The survey instrument is available from FCA’s National Center on Caregiving upon request.
complete and were conducted between June 6-12, 2002. The five foundations participating in the qualitative, telephone interviews were:

- The AARP Andrus Foundation
- The Archstone Foundation
- The Grotta Foundation
- The Robert Wood Johnson Foundation
- The Rose Community Foundation

Each foundation representative was asked the following questions to better understand their perspectives about family caregiving as a grantmaking area:

1) *Is family caregiving currently an important area for grantmaking? If so, why? If not, why not?*

2) *Now that there is some Federal funding for family caregiver support – under the Older Americans Act, National Family Caregiver Support Program – how will this impact your foundation’s grantmaking in this area?*

3) *What recommendations would you make to other grantmakers that are developing initiatives to support family caregivers?*
Survey Results

Of the 243 foundations (unduplicated) that received the survey, 117 foundations responded, resulting in a 48% response rate. Responding foundations were located in 30 states and the District of Columbia.

Nineteen foundations, or 16% of the total sample, expressed no interest in family caregiving as part of their current or future aging or health grantmaking areas and were thus excluded from the analyses in this report. A description of the total sample of 117 foundations appears in the Appendix.

The remaining 98 foundations identified themselves as grantmakers with a current or potential interest in funding family caregiving initiatives. The analyses which follow are drawn from these 98 “caregiver-interested” foundations.

A. Background Characteristics of Foundations:

The 98 foundations varied widely in their basic background characteristics, including type of foundation, total assets, total grantmaking funds, and geographic focus of grantmaking.

Foundation Type (N=98)

2 By comparison, the 1999 Grotta survey had a 14% response rate with 69 funders out of 500 returning the questionnaire.

3 In 1999, 38% of the 69 funders responding to the Grotta survey did not identify themselves as grantmakers in family elder caregiving.

4 16 of the 98 foundations did not currently fund caregiving programs nor could they predict their future interest in funding for family caregivers. We elected to include these foundations in the analyses because they did not rule out future interest in funding programs and services to support family caregivers.
Approximately half of the “caregiver-interested” grantmakers in aging and health that responded to the survey identified as private foundations. Eight in ten of the foundations considered themselves to be private foundations (51%), public charities (22%) or community foundations (8%).

Foundation Assets in 2000 (N=98)
M= Millions; B=Billions

Over three quarters (77%) of the foundations reported assets between $10 and $500 million for the year 2000. The median amount of foundation assets in 2000 was $60 million.

In terms of size of total grant program in 2000:

- 74% of foundations provided grants totaling $10 million or less.
- The median amount of funds granted by the foundations was $3 million.
- The median number of grants awarded was 45.
Over half (54%) of the foundations had a local grantmaking focus. In addition, more than a third of the foundations identified as having a regional or statewide focus (38%), and nearly a fifth of the foundations (18%) had a national grantmaking focus. Some foundations identified as having more than one geographic focus for their grantmaking (i.e. local and regional).

B. Access to and Use of Information on Family Caregiving:

“Funders, be they government or private, [need to] get involved with primary associations dealing with caregiver issues, such as Grantmakers in Aging, get on listservs, get educated about what’s out there.”

“There’s lots of information but little time. [We need] help organizing information.”

Current Access to Information on Family Caregiving (N=98)
The vast majority of foundations indicated that they were currently receiving information on family caregiving. When asked to assess the degree to which their foundation currently has access to information on family caregiving, over 80% of the foundations responded that they had access to “some” (61%) or a “great deal” (20%) of information. Less than one in five foundations noted that they currently had “little access” (16%) or “no access” (3%) to information on caregiving.

Print media and web-based delivery were the most preferable and useful modes of information delivery on family caregiver issues. More than two out of three (68%) foundations rated fact sheets (1 to 4 pages in length) as their top format for receiving information. Websites (58%), to visit on one’s own, was the second highest format preferred. Audio or videotape formats and teleconferences were chosen by a surprisingly small percentage of the foundations (5%-6%).

Model caregiver programs, resources and/or services available to caregivers, and information about caregiver sub-groups top the list of caregiver-related topics about which foundations would like to learn more. Foundations were asked to identify topics related to caregiving about which they would like more information. Responses revealed that foundations were most interested in receiving information about caregiver programs that have been proven to work well. They were also interested in caregiver needs generally as well as the resources and services caregivers required to best meet those needs. Many foundations requested information about particular sub-groups of caregivers related to ethnicity, sexual orientation, age, and disability status.
The top family caregiving topics about which foundations requested more information, in order of interest, were:

1. Model programs/Best practices
2. Caregiver resources and/or services
3. Caregiver sub-groups (e.g. ethnicity, gay/lesbian, disability)
4. Caregiver needs/Needs assessments
5. Policy/Legislation (tied with 6)
6. Funding/Financial issues
7. Caregiver well being (tied with 8)
8. Caregiver research

The following comments reflect specific caregiver topics of interest to many of the foundations:

- “We are interested in how [family caregiving] needs differ between various cultures/ethnicities.”

- “What are some of the new initiatives being funded to help caregivers cope? What is being done on the national and state policy levels?”

- “What are some of the best practices to support caregivers? What are some models that have been tested for positive success in teaching caregivers and providing them with support?”
C. Awareness of the National Family Caregiver Support Program (NFCSP):

“We are trying to work collaboratively with our local AAA’s [Area Agencies on Aging] to leverage NFCSP dollars. We want to do a needs assessment to find out what caregivers want and need before we just ‘do’ something.”

“We’re really trying to share information and to avoid duplication and try to leverage our dollars…and serve more people.”

Awareness of NFCSP (N=98)

<table>
<thead>
<tr>
<th>Awareness Level</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Fully aware</td>
<td>6%</td>
</tr>
<tr>
<td>Somewhat aware</td>
<td>45%</td>
</tr>
<tr>
<td>Not at all aware</td>
<td>49%</td>
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</tbody>
</table>

Foundations were generally unaware of the Administration on Aging’s National Family Caregiver Support Program (NFCSP). When asked about their awareness of the NFCSP, nearly half (49%) of the foundations replied that they were “not at all aware” of the federal program. Forty-five percent indicated that they were “somewhat aware”; only six percent were “fully aware” of the NFCSP.

Not surprisingly, foundations most involved in family caregiving currently were the most aware of the NFCSP. Of the seven foundations which currently had a specific grantmaking focus on family caregiving and also anticipated the same or greater funding interest in the future, four were “somewhat aware” and two were “fully aware” of the NFCSP. Of those foundations that had not considered family caregiving in their current grantmaking programs, 65% were totally unaware of the NFCSP. Similarly, of the 35 foundations that could not predict their future interest in family caregiver grantmaking, 74% were unaware of the NFCSP.

National foundations had a higher rate of awareness of the NFCSP compared to local and regional-based foundations. Approximately 17% of the national foundations indicated that they were “fully aware” of the NFCSP. However, only four percent of the foundations with a local focus were “fully aware” of the initiative, and none of the regionally focused foundations claimed to be “fully aware” of the NFCSP.
D. Current Focus on Family Caregiving:

“Given the changing demographics and the existing populations, this issue will require additional attention in the near future. Our foundation is aware of this need.”

“We are doing a lot of programming around long-term care and supports in general around the aging of the population and the increased need for people with chronic conditions.”

“I see a growing recognition among the funders that, if you care about aging and eldercare, then you have to care about the caregivers.”

**Current Grantmaking Focus on Family Caregiving**

(N=98)

- Specific caregiving funding focus: 8%
- Supports caregiving within home & community-based care: 71%
- No current focus on family caregiving: 20%

**Most (71%) of the foundations currently supported family caregiver initiatives within the broader context of funding programs and services related to home and community-based long-term care for older persons and their families.** When asked to choose which statement most accurately reflected the foundation’s current grantmaking focus regarding family caregiving, respondents chose between the following options:

- Our foundation has not considered family caregivers at all as part of our aging or health grantmaking areas.
- Our foundation supports home and community-based care, which includes programs and services designed to assist family caregivers.
- Our foundation has a specific grantmaking focus on family caregiving.

One in five (20%) grantmakers said their foundations had not considered caregiving as part of their current aging or health grantmaking areas. Additionally, another eight percent of the foundations indicated that they had a specific grantmaking focus on family caregiving.
The eight foundations with a current family caregiving focus are:

- AARP Andrus Foundation, Washington, DC
- Altman Foundation, New York, NY
- Archstone Foundation, Long Beach, CA
- Community Foundation for Southeastern Michigan, Detroit, MI
- Mather LifeWays, Evanston, IL
- Paso del Norte Health Foundation, El Paso, TX
- Rose Community Foundation, Denver, CO
- The Sunflower Foundation, Topeka, KS

Local and regionally-based foundations were more likely than national foundations to have a current grantmaking focus on family caregiving for older persons, either as a specific area of support or as part of a broader grantmaking focus on home and community-based care for older persons (including programs and services to assist family caregivers).

- 87% of locally-based foundations had a current grantmaking focus on family caregiving
- 81% of foundations with a regional/state focus had a current grantmaking focus on family caregiving
- 67% of nationally-based foundations had a current grantmaking focus on family caregiving

**Activity Level of Family Caregiving Support in Past 2 Yrs (N=98)**

<table>
<thead>
<tr>
<th>Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very active</td>
<td>18%</td>
</tr>
<tr>
<td>Somewhat active</td>
<td>48%</td>
</tr>
<tr>
<td>Not at all active</td>
<td>34%</td>
</tr>
</tbody>
</table>

*Foundations generally expressed a moderate level of activity in funding family caregiving initiatives in the past two years.* When asked how active their foundation had been in the past two years in funding projects and programs that support family caregivers, nearly half (48%) of the foundations responded as being “somewhat active”, while nearly a fifth (18%) considered themselves to be “very active”. However, one-third (34%) of the foundations responded as being “not at all active” in funding family caregiving projects in the previous two years.
Further analysis revealed that 79% of the foundations that currently supported family caregiving projects had also been active in funding family caregiving initiatives in the past two years. Not surprisingly, the vast majority of these foundations (89%) supported caregiving within the broader context of home and community-based care, as opposed to having a specific caregiving funding focus.

E. Future Interest in Family Caregiving:

“We will not have a major focus on caregiving issues, but see it as an important part of our overall strategies in community-based long-term care.”

“As the federal government picks up more caregiving-related programming and services...foundations’ tendency will be to move into ancillary areas.”

Future Caregiving Interest
(N=98)

- Greater interest: 29%
- Cannot predict: 35%
- Same interest: 36%

Three out of four (75%) current funders expected their interest in funding family caregiving initiatives would be the same or greater over the next three to five years. When asked to anticipate their foundation’s interest in funding family caregiving initiatives in the near future (i.e. next three to five years), 29% of the foundations predicted “greater interest”, 36% said their interest would remain the same, and another 35% of foundations could not predict their future interest. Only three of the grantmakers currently funding family caregiving programs or services specifically or as part of broader strategies indicated that their interest would lessen in the coming years.

Of the 63 foundations that had been either “somewhat active” or “very active” in funding family caregiving in the past two years, 81% expected to have the same or greater interest in funding family caregiving in the next three to five years. Of the 17 foundations that defined their support of family caregiving programs in the past two years as “very active”, 82%
anticipated the same or a greater level of interest over the next three to five years. Of the 46 foundations that defined their support of family caregiving programs in the past two years as “somewhat active”, 80% anticipated the same or an even greater level of interest in supporting family caregiving initiatives in the near future.

In general, the more interest the foundation had in funding family caregiving currently, the higher the level of projected interest in funding family caregiving in the future. Of the eight foundations that currently had a specific grantmaking focus on family caregiving, 88% anticipated the “same interest” or “greater interest” in funding family caregiving initiatives over the next three to five years. For the 70 foundations supporting family caregiving within the context of home and community-based care, 74% expected the same or greater interest in family caregiving. Of the 20 foundations with no current focus on caregiving, the vast majority (80%) could not predict their future interest in funding family caregiving.

Foundations were also asked how likely their foundation would be to pursue the following strategies over the next three to five years:

- Designate family caregiving as a funding priority
- Support aging and long-term care initiatives, but not designate family caregiving as a separate funding priority
- Not fund family caregiving projects at all

Foundations were most likely to anticipate supporting family caregivers within the larger strategy of support for aging and long-term care initiatives, rather than designating family caregiving as a specific funding priority. Nearly three-quarters (73%) of foundations responded that they were “somewhat likely” or “very likely” to support aging and/or long-term care initiatives in the future. Foundations were much less likely to prioritize funding for family caregiving and were also much less likely to provide no funding for family caregiving entirely. About one in four (27%) foundations said they were “somewhat likely” or “very likely” to designate family caregiving as a distinct funding priority in the coming years. On the other hand, 19% of the grantmakers indicated that their foundation was at least “somewhat likely” to not fund family caregiving at all.

Foundations which had been “very active” in funding family caregiving in the past two years, showed strong interest in prioritizing family caregiving funding in the near future. More than two-thirds (69%) of the very active foundations were “somewhat likely” or “very likely” to designate family caregiving as a funding priority in the next three to five years.

Virtually all (91%) of the 32 foundations which had been “not at all active” in funding caregiving projects and programs in the past two years, were “somewhat unlikely” or “very unlikely” to designate family caregiving as a funding priority in the next three to five years. On the other hand, this same “not at all active” group of foundations was at least somewhat likely to provide support for aging and long-term care initiatives, including programs to support family caregivers. Over half (58%) of the foundations were “somewhat likely” or “very likely” to support aging and long-term care initiatives, but not designate family caregiving as a separate funding priority in the next three to five years.
Grantmakers indicated assessment of need in the community as the most influential factor to shape their future grantmaking in caregiving, followed by increased recognition of caregiving as a pressing social concern and the foundation’s pre-established priorities. Grantmakers were offered a list of factors that may influence their foundation’s decision making about grantmaking for family caregivers in the near future (i.e. next three to five years). In addition to the top three factors noted above, three other influential areas identified were the opportunity to make a visible difference (86%), model program replication (84%) and grantmaker collaboration (81%).
When asked to identify the single most important factor from the list above that would influence their foundation’s decision making about future grantmaking for family caregiving, the top five factors identified in order of importance were:

1. Foundation’s pre-established priorities
2. Assessment of need in the community
3. Opportunity to make a visible difference
4. Increased recognition of family caregiving as a pressing social concern
5. Personal interest of Board

Local and regional/state foundations anticipated more reliance upon pre-established foundation priorities and community need in determining future grantmaking decisions when compared with national grantmakers. While community need is identified as an important factor to the national grantmakers as well, making a visible difference and following Board interest were of higher importance to the national group of foundations.

Foundations with a local grantmaking focus were most influenced by:

1. Foundation’s pre-established priorities (28%)
2. Assessment of need in the community (23%)

Foundations with a regional/state grantmaking focus were most influenced by:

1. Foundation’s pre-established priorities (24%)
2. Assessment of need in the community (19%)

Foundations with a national grantmaking focus were most influenced by:

1. Opportunity to make a visible difference (22%)
2. Personal interest of Board (22%)
“We need to figure out what it is that really is innovative and doable, particularly at the community level, and see how we can help people move forward with those things.”

“I think that this notion of disseminating models, particularly if foundations were involved in them in other places, is very important.”

Future Family Caregiving Priority Funding Areas (N=98)

- Implement local/regional strategy to inform public about family caregiving & LTC: 58%
- Replicating existing, effective model programs: 57%
- Promote new model programs: 54%
- Promote capacity-building among aging network: 48%
- Conduct training of family caregivers: 45%
- Conduct training of service providers: 45%
- Serve as convener to frame policy issues & consider options: 38%
- Collaborate with government: 32%
- Promote policy changes to support family caregivers: 27%
- Promote web-based programs: 22%
- Conduct policy analyses: 17%
- Conduct caregiver research: 15%
- Develop caregiver assessment tools: 14%
- Implement national strategy to inform public about family caregiving & LTC: 9%
While foundations indicated a wide range of caregiving priorities over the next three to five years, their top three priorities for funding were: 1) Implementing local/regional strategies to inform the public about family caregiving; 2) Replicating existing, effective model programs; and 3) Promoting new model programs. Promoting capacity-building among the aging network (i.e., Area Agencies on Aging) and conducting training for family caregivers and/or service providers who work with family caregivers were also anticipated to be priority funding areas for nearly half the sample (45%-48%).

Foundation priorities to support family caregivers in the future differ by the geographic scope of the foundation. However, all grantmakers, whether local, regional or national, identified replicating existing, effective models as a relatively top priority over the coming years. Not surprisingly, local and regional foundations were more interested in implementing local strategies to inform the public about family caregiving compared with nationally-focused foundations.

Locally-focused foundations were most likely to support the following types of family caregiving projects/programs:

1. Replicate existing, effective models of caregiver support (62%)
2. Promote new models that support family caregivers (55%)
3. Implement a local/regional strategy to help inform family and friends about caregiving and long-term care (55%)

Foundations with a regional/state grantmaking focus were most likely to support the following types of family caregiving projects/programs:

1. Implement a local/regional strategy to help inform family and friends about caregiving and long-term care (76%)
2. Replicate existing, effective models of caregiver support (57%)
3. Conduct education & training for family caregivers (51%)
4. Serve as a convener of policymakers, practitioners, researchers & others to frame policy issues in caregiving & consider policy options to address problems caregivers face (51%)
5. Promote capacity-building among the aging network (e.g. Area Agencies on Aging) (51%)

Nationally-based foundations were most likely to emphasize projects/programs in the following areas:

1. Promote new models that support family caregivers (44%)
2. Replicate existing, effective models of caregiver support (44%)
3. Conduct training for service providers who work with family caregivers (44%)
“There’s certainly [foundation] activity going on in family caregiving…but it’s hard to figure out what the philanthropic angle is on it.”

“We value partnering with other organizations on funding, whether it’s government or private funders. And so the fact that the government is stepping up to the plate on some of these issues is a positive, and I expect that we will continue to try and look for ways to streamline or fit in what we do with what others do in a way that makes sense.”

**Interest in Attending Grantmakers Meeting**

N=98

- Yes: 28%
- Maybe: 42%
- No: 30%

*Seven out of ten (70%) foundations expressed potential interest in attending an invitational grantmakers meeting to explore the synergy of the public and independent sectors in supporting family caregiving.* Foundations were asked if they would be interested in attending a meeting with other foundation executives in Washington D.C., convened by the U.S. Assistant Secretary for Aging, to explore public/private collaboration in supporting family caregiving. Only 30% of the grantmakers expressed no interest in participating in such a meeting.

In a promising trend, over half of the foundations (56%) with no current focus on family caregiving were also potentially interested in attending such a meeting.
Grantmakers’ Perspectives

This section presents the perspective of foundation leaders on family caregiving as a grantmaking area. To complement the written survey, telephone interviews were conducted with a sample of five foundations recognized for their leadership in aging, health, and/or support for family caregiving at the national, state, or local levels. The foundations and their representatives included:

- **The AARP Andrus Foundation**, Washington, D.C.
  *John Feather*, Director and President, Grantmakers in Aging

  The AARP Andrus Foundation was established in 1968 in memory of AARP founder, Dr. Ethel Percy Andrus. The foundation is committed to making a positive difference in the lives of older adults across the country through funding aging-related research and educational grants. It is one of the few national grantmaking foundations continuing to focus solely on aging issues.

- **The Archstone Foundation**, Long Beach, CA.
  *Mary Ellen Courtright*, Vice President and Program Officer

  The Archstone Foundation was created in 1985 as a private grantmaking foundation with a focus on the broad issues of health. In 1996, the Archstone Board of Directors decided to redirect the funding priorities from health concerns in the entire life cycle to aging issues, including family caregiving. The majority of the foundation’s funds are directed to programs in Southern California. Demonstration projects and programs with regional or national impact are also considered from other parts of the country.

- **The Grotta Foundation**, South Orange, NJ.
  *Susan Friedman*, Executive Director

  The Grotta Foundation was created in 1993, charged with the mission of expanding and enhancing services for older persons in New Jersey and their families. For the past six years, the foundation has had a major focus on national, state, and local policy, planning, and service innovations that assist family caregivers of older persons.

- **The Robert Wood Johnson Foundation**, Princeton, NJ.
  *Karen Davenport*, Program Officer

  The Robert Wood Johnson Foundation (RWJF) was established as a national philanthropy in 1972, and today is the largest foundation in the country devoted to improving the health and health care of all Americans. The foundation concentrates grantmaking in four areas: to assure that all Americans have access to basic health care at reasonable cost; to improve care and support for people with chronic health conditions; to promote health communities and lifestyles; and to reduce the personal, social and economic harm caused by substance abuse.
• **Rose Community Foundation**, Denver, CO.
  
  *Therese Ellery, Program Officer*

Rose Community Foundation was established in 1995. The foundation provides grants to organizations in the Greater Denver community. It concentrates its resources in five key program areas: aging, child and family development, education, health, and Jewish life. In the aging area, priorities include: public awareness and information; support for caregivers; coordination of independent living services for older adults; and collaboration among providers, both public and private, and partners in the community.

Telephone interviews were conducted with representatives from each of the five foundations between June 6-12, 2002. On average, the interviews took 15 minutes to complete. The foundation representatives were sent the questions beforehand to guide the conversation. Three questions were asked:

1) *Is family caregiving currently an important area for grantmaking? If so, why? If not, why not?*

2) *Now that there is some Federal funding for family caregiver support – under the Older Americans Act, National Family Caregiver Support Program—how will this impact your foundation’s grantmaking in this area?*

3) *What recommendations would you make to other grantmakers that are developing initiatives to support family caregivers?*

A summary of responses is highlighted below.

**Is family caregiving currently an important area for grantmaking? If so, why? If not, why not?**

According to John Feather, the AARP Andrus Foundation has been involved in caregiving issues and caregiver research for a long time. More recently, the Foundation has begun examining issues like Alzheimer’s home care and what family members need to know to keep loved ones at home. In the foundation world, “less than two percent of philanthropy is still going to aging in general” commented Feather, “and I don’t see [family caregiving] as big an issue as it probably needs to be.” He further noted that while funders recognize the importance of family caregiving “some other issues seem to be more central to foundations at the moment.”

Mary Ellen Courtright of the Archstone Foundation noted that family caregiving “continues to be a very important aspect of our work.” According to Courtright, “The issue has been on our agenda for 10 years now and I fully expect that it will continue to be a priority area for us.” As for grantmaking in the field of aging in general, Courtright observed that she keeps seeing the issue of family caregiving coming up, either on the Grantmakers in Aging listserv, in discussions among foundation staff, in topics that funders want to have addressed in their meetings, and
programs that people want to share as best practices. Courtright commented that, “I see caregiving staying on the agenda for a lot of the foundations who are part of Grantmakers in Aging. There is a recognition – growing among the funders – that if you care about aging and eldercare, then you have to care about the caregivers.”

Susan Friedman of the Grotta Foundation shared that her foundation has been supporting family caregiving initiatives for six years now. Grotta, however, is shifting focus to examine home-based services for older persons, which are implicitly supportive of caregiving, but are not explicitly focused on this population. Friedman explained that the State of New Jersey “has increased its funding significantly in caregiving, and with the National Family Caregiver Support Program (NFCSP), that the state has expanded further into providing support services for family caregivers. As the federal government picks up more caregiving-related programming and services, such as educational initiatives or support groups, foundations’ tendencies will be to move into other home and community-based areas to support older persons and their families.” Friedman observed that family caregiving is still an important topic for foundations in the aging and health areas, particularly in conducting trend analyses and other research. However, she noted that “fund ares are going to look to see what government is doing, and if government is going to be increasing dramatically its support, funders will tend to partner with government, but ultimately move to new areas.”

Karen Davenport of The Robert Wood Johnson Foundation commented that there’s certainly foundation activity in family caregiving issues, but it is a “secondary area in some ways… because it is hard to figure out what the philanthropic angle is on it.” She noted that her foundation is doing a lot of programming around long-term care and supportive services in general in regards to the aging of the population, as well as the increased need for care and support for people with chronic conditions. Davenport added that, “Family caregivers are a huge part of how people receive the help that they need, and thinking about how you can do projects that support family caregiving is obviously an important piece of that.” Workforce initiatives to strengthen formal caregivers and support in minority communities to strengthen informal caregivers are grantmaking areas to be pursued by her foundation, she said.

Therese Ellery of the Rose Community Foundation commented that given the demographics and population explosion for the 60 and over population, family caregiving is going to become an increasingly important issue. Ellery shared that family caregiving “is a critically important area for grantmaking” and one of her foundation’s priorities. “More foundations,” she said “need to look at family caregiving issues locally and nationally because private funding in the aging area is very small in comparison to other funding areas.”

Now that there is some Federal funding for family caregiver support – under the Older Americans Act, National Family Caregiver Support Program– how will this impact your foundation’s grantmaking in this area?

John Feather, of the AARP Andrus Foundation, said, “given the need, the Federal funding is so minimal that it’s hard to see how it’s really going to have a major impact. I don’t see any funders turning away from the issue because the federal government’s picked up this small amount.”
According to Feather, “foundations really think of themselves as conveners. A lot of foundations really enjoy doing public/private partnerships because the foundation is generally seen as kind of a neutral party, so if that is something that the government is interested in doing, it is a very logical role to encourage those kinds of partnerships with philanthropy.”

Mary Ellen Courtright, of the Archstone Foundation, reflected that she doesn’t see the Federal funding impacting her foundation “because [caregiving] is already a priority and they value partnering with other organizations on funding, whether it is government or private funders. “The fact that the federal government is stepping up to the plate on family caregiving is positive,” she said. “I expect we will continue to try and look for ways to streamline or fit in what we do with what others do in this area in a way that makes sense,” she concluded.

Susan Friedman of the Grotta Foundation commented that “the Older Americans Act dollars [for family caregiving] are minimal.” She believes that it is really the state general fund dollars that state foundations like Grotta look at closely. Friedman added that “national foundations that are interested in supporting the ‘movement’ around caregiving, or the research around caregiving, will likely continue their support and grow because they have more to look at.” She noted, however, that if states are doing more to deliver respite, education, and support services, local foundations will likely look to fill other voids. She went on to say that her foundation has received an increasing number of caregiving requests at a time when they are beginning to pull back a little bit from funding in this area. “On the other hand,” she said, “I think what states do [to support family caregiving] is going to have an impact and that will vary from state to state.”

Karen Davenport of The Robert Wood Johnson Foundation reflected that she believes the Federal funding for family caregiver support generally is positive. “It means that you have to more carefully coordinate what you are doing, and that you don’t want to replicate funding.” It also means that you “look to define your niche a little bit more carefully and see how it interacts with other efforts that are going on,” she added. “But I don’t think it means that we want to pull out of it; if anything, we are probably more interested in getting into this area of funding. Particularly given how modest the Federal funds are, and trying to think about how those limited public dollars can most effectively be used, it might be something that foundations in particular can be helpful with,” Davenport concluded.

Therese Ellery of the Rose Community Foundation commented that her foundation is really excited about the opportunity to work with the Area Agencies on Aging in her community. They are currently exploring partnership efforts to do a needs assessment of caregivers. “We feel that we shouldn’t be starting new programs and services unless we go to the caregivers themselves and ask them about what they think and what they need and what will work for them,” she said. Ellery commented that in her community, the foundation sees the biggest need to be in outreach, so family caregivers know where to go, what to ask, and how to get connected. She added that foundations have a role to play to help those families who fall through the cracks, generally moderate income caregivers whose loved ones have too much income for public benefits but yet can’t afford to pay out-of-pocket for support services. Other areas she suggested that foundations can focus on to complement Federal funding would be to assist employed caregivers by working with corporations and businesses, and trying to figure out the best use of technology and best practices to meet the needs of family caregivers.
What recommendations would you make to other grantmakers that are developing initiatives to support family caregivers?

John Feather, of the AARP Andrus Foundation, made the recommendation that “since there’s a lot that has been done to support family caregivers, don’t start over.” Feather commented that “there is a huge need to figure out what it is that really is innovative and doable, particularly at the local community level, and see how we can help people move forward with those efforts.” He added that “one thing we’ve learned at Grantmakers in Aging, more than anything, is that what really works with philanthropy and foundations is not coming in and saying something like, ‘what you need to do is start a caregivers program.’ What works is that you already do a grandparents taking care of grandchildren program, for example, so why don’t you think about whether there are other caregiving aspects to that and build on it.”

Mary Ellen Courtright, of the Archstone Foundation, said that her major recommendation to funders would be to look at what models are out there and build upon them. Courtright said that she would “encourage funders to look first at what’s already been created, what seems to be working, how can they build on that within their local communities, and how can they look at replicating what works.” She added that funders “should look at ways to build on models that work, look at the networks that have been evolving around the country addressing caregiving issues, and then look at how to partner with other funders or government funding, to see if you can start to create some basic continuity of supports.”

Susan Friedman, of the Grotta Foundation, suggested that foundations should begin in partnership with local and state government, because, ultimately, “to put things in place in communities that will have some longevity, you have to really impact state legislation and even local tax-levy dollars.” Friedman commented that what her foundation found is that the first step in funding and reaching caregiving communities is in the area of outreach. “Because most caregivers, even now,” she said “are hidden.” Clearly, she added, there also needs to be more funding for research on caregiving. Lastly, she noted that an emerging area in caregiving is the issue of multigenerational caregiving. “I know that there are major lobbies now in the child and youth grantmaking sectors saying that there’s too much attention being placed on aging, and I think this is the way to bridge it,” she noted.

Karen Davenport of The Robert Wood Johnson Foundation said the major recommendation would be “to partner with us.” She explained that partnerships help to expand the reach of whatever is done, and if foundations and government are looking at the same kinds of activities it could be complimentary and beneficial to partner. Davenport also added that grantmakers could look at target marketing within existing areas of funding. For example, she said that if a foundation does a lot of grantmaking in mental health, they might want to look at the complex needs of family caregivers in families that are coping with severe mental illness. “These might be very productive areas to be working in,” she added.

Therese Ellery, of the Rose Community Foundation, said that “you should always go to the group you want to help and ask them what they think.” She also felt that it was important to talk to other grantmakers, and use resources like the Grantmakers in Aging listserv, so that funders that have some experience in caregiving can share what they know. Ellery also recommended
that funders document what works and what doesn’t work so that best practices can be identified and replicated. Lastly, she said that she would “encourage other grantmakers to give more money to initiatives supporting caregivers.” Ellery pointed out, “Only two percent of foundation dollars go to aging issues…We would encourage grantmakers to give more money and pay more attention to the needs of family caregivers.”
Conclusions and Recommendations

♦ *Family caregiving is on the funding agenda for the great majority of grantmakers who responded to this survey.* Results support previous research (Gutheil & Chernesky, 1999) that current funders in family caregiving expect their interest in funding in this area to remain the same or greater over the next three to five years. Grantmakers not currently funding caregiving initiatives but expressing potential support, generally anticipate greater interest in future funding of family caregiving, either as part of a broader strategy to support older persons and their families or as an explicit priority.

♦ *Grantmakers are most likely to fund family caregiving, now and in the future, within the broader context of home and community-based long-term care for older persons and their families.* Most (71%) of the foundations described themselves as currently supporting home and community-based care which includes programs and services designed to assist family caregivers, and the majority (73%) anticipate continuing this strategy over the next three to five years.

♦ *While most of the foundations in this study reported interest in caregiving, a sizeable proportion had no current grantmaking focus on family caregiving for older persons.* About 20% of the 98 “caregiver-interested” foundations had not considered family caregiving as part of their current aging or health grantmaking areas. This is a group, in particular, for which more knowledge about and access to information on caregiving may be especially important in influencing their grantmaking priorities in the future.

♦ *Most grantmakers with a current focus or potential interest in caregiving have some access to information on this population.* Surprisingly, 19% of the foundations – all of which are members of either Grantmakers in Aging or Grantmakers In Health -- indicated they had little or no access to information on family caregiving.

♦ *Fact sheets, websites and white papers/articles topped the list of most useful modes of information delivery on family caregiving issues.* The topics of most interest to foundations were model programs and “best practices”; the range of caregiver needs and resources and services to best meet those needs; and information about special caregiver populations (e.g., cultural/racial groups, lesbian/gay issues). Utilizing effective ways to disseminate this information to grantees is paramount to ensure that foundations are aware of issues and growing trends affecting family and informal caregivers.

♦ *Local and regional foundations showed a high level of interest in family caregiving overall.* For these grantmakers, support of caregivers grows out of their interest in meeting community needs. This finding supports previous research from the Grotta study (Gutheil & Chernesky, 1999).

♦ *More foundations can be expected to designate family caregiving as a funding priority in the near future.* While only 8% of the foundations indicated that they had a current, specific grantmaking focus on family caregiving, 29% of the grantmakers anticipated that their foundation would designate family caregiving as an explicit funding priority in the next three to five years.
- **Foundations are likely to fund family caregiving initiatives in the future if the community need for family caregiver support is seen as high and if family caregiving is more widely recognized as a pressing social concern.** The aging network and other leaders in the caregiving movement have an opportunity to shape grantmakers’ agendas to support and strengthen caregiving families. To be successful, it is important that funders – in both the public and private sectors -- pursue targeted funding strategies to move the caregiving agenda forward. Examples include: 1) public education campaigns to increase recognition; 2) policy research and analysis to generate valuable data to support the growing and diverse needs of caregivers; 3) evaluations of current caregiver programs to demonstrate they work and can be replicated; and 3) advocacy efforts to build local, state and national coalitions.

- **Foundations expressed a high interest in replicating existing, effective model programs or promoting new model programs to sustain families in their caregiving role.** This was also an area about which foundations requested more information. It is therefore imperative that service providers who work with family caregivers collect outcome data to document the effectiveness of programs and services. It is also important that best practices in current caregiver programs and ideas for innovative, new caregiving programs be disseminated to grantmakers at the national, regional and local levels.

- **While foundations had a substantial interest in family caregiving, they were not well informed about the National Family Caregiver Support Program (NFCSP).** There is a clear need for the federal government to more widely disseminate information about this new national program to the private philanthropy community. Foundations are interested in leveraging dollars and collaborating when possible. If they are better informed about the NFCSP, they may be more likely to increase funding or form partnerships with the public sector in the family caregiving arena to have a greater impact. Providing information about the NFCSP to grantmakers in aging and health may be of particular importance for those foundations that have an interest in family caregiving but have not yet committed resources to this area.

- **Partnerships – among funders and between the public and private sectors – are important factors in determining future foundation support in caregiving.** Grantmaker collaboration was viewed by 84% of the foundations as a factor to influence their foundation’s grantmaking decisions for family caregiving over the next three to five years. Two-thirds (67%) viewed public/private collaboration as a key factor in future funding decisions. One of the most effective ways to leverage foundation dollars is by partnering and collaborating in the development of caregiver initiatives.

- **Most foundations in this survey expressed interest in meeting with government entities and other grantmakers to explore the synergy of the public and independent sectors in supporting family caregiving.** Attaining long-term sustainable solutions to support and strengthen family and informal caregivers at the national, state and local levels will take a partnership of both public and private funders. Foundations are cognizant of the importance of partnering and interested in pursuing further collaboration.
References


Appendix 1

Description of Total Sample of Foundations:

Of the 243 foundations that received the survey, 117 foundations responded overall, resulting in a 48% response rate. The total sample of 117 foundations was very similar in makeup to the sub-sample of the 98 “caregiver-interested” foundations analyzed in this report. Key characteristics of this larger sample of foundations include the following:

♦ The vast majority (84%) of foundations with an interest in aging and health responding to the survey also identified themselves as grantmakers with a current or potential interest in funding to support family caregivers.

♦ Only 16% of the total sample of foundations expressed no interest in family caregiving as part of their current or future funding priorities.

♦ Approximately seven out of ten (71%) grantmakers had a current grantmaking focus on family caregiving for older persons, either as a specific grantmaking focus or as part of broader support for home and community-based care including programs and services designed to assist family caregivers.

♦ The majority of foundations (58%) had been either “somewhat active” or “very active” in funding programs and projects that support family caregivers in the previous two years.

♦ Over half (53%) of the foundations identified as private foundations and as having a local grantmaking focus (56%).

♦ Almost three-quarters (74%) of the sample reported assets between $10 to 500 million in 2000.

♦ More than half (57%) of the foundations made grants totaling $5 million or less in 2000.

♦ Nearly half (48%) of the grantmakers had no awareness of the National Family Caregiver Support Program (NFCSP) administered by the U.S. Administration on Aging.

♦ Nearly two out of three (65%) foundations anticipated the same or greater interest in funding family caregiving initiatives in the next three to five years.